

# Children with Special Health Care Needs in NORTH DAKOTA

## Who are Children with Special Health Care Needs?

Children with special health care needs (CSHCN) have or are at increased risk for a chronic physical developmental, behavioral, or emotional condition. They usually require health and related services of a type or amount beyond that required by children generally. In fact, CSHCN account for 40% or more of medical expenditures for children overall\*.



## A Personal Look at a Family in North Dakota:

Cassie Keller is the mom to two sons, Carter and Carson. When Cassie was pregnant she found out that Carson had Trisomy 13. Cassie was told that Carson would not survive birth and that she should think about having an abortion. Cassie and Matt (Carter's father) chose to continue the pregnancy, even though they knew it would be difficult. Cassie asked her physician if she should purchase things like a car seat or a few clothes in case Carson did survive birth. She was told that this would not be necessary since there was no chance of his survival.

On October 22, 2009, Cassie was not feeling well. She went to the emergency room to find out that she had pneumonia. She was admitted immediately. The doctors did not know if she would survive the night. They intubated her and made the decision to perform an emergency c-section to help save Cassie's life. Since Carson wasn't expected to live, no extra medical care was provided to keep him alive. Instead the doctors laid Carson on Cassie's chest and he began breathing. More than once Carson stopped breathing. Each time he was laid on Cassie's chest he began breathing again. Carson went home with Matt when he was 2 days old. Cassie stayed in the hospital until Carson was 21 days old. Hospice care was set up for Carson at his discharge. When Cassie got out of the hospital she took Carson to a pediatrician to find out more about Carson's needs. Carson had needs, but he was thriving and had already survived a month more than anyone expected. The family had not been connected to any other supports or medical care at this time, only hospice.

At a WIC appointment it was suggested that the family get connected to Family Voices of North Dakota (FVND). FVND connected the family to the Human Service Center (for respite care instead of hospice care), to Early Intervention, and to Parent to Parent Support. Three months ago Cassie wrote the following, "They have made a huge impact on my life and so many others. I don't know how long my son will be here but what I do know is that he is a miracle and every day is a blessing with him, and no matter what happens I know with FVND have such a huge family full of support and Matt and I will never go through anything alone." Unfortunately, Carson passed away in January. He was 14 months old. Carson made a huge impact on many. Their family story will live on as we try to improve systems and continue to promote support for parents situations such as Cassie's.

## By the Numbers: CSHCN in North Dakota\*

<b>Prevalence of Children with Special Health Care Needs (CSHCN), among all children age 0-17</b>	<b>12.2%</b>	<b>16,541</b>
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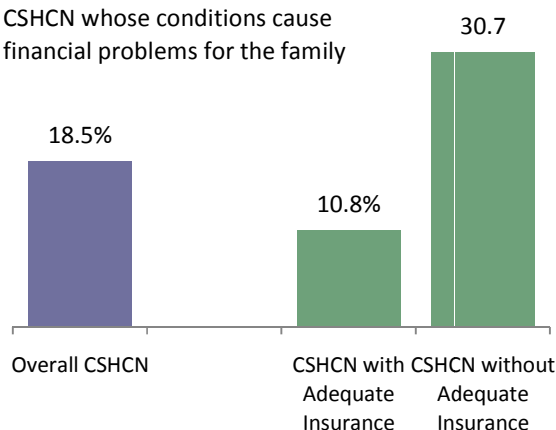
	<b>% of CSHCN</b>	<b># of CSHCN</b>
<b>Currently insured CSHCN whose insurance is inadequate</b>	<b>25.9</b>	<b>4,066</b>

### Impact of CSHCN on the Family:

<b>CSHCN whose families pay \$1,000 or more out of pocket in medical expenses per year per child</b>	<b>21.9</b>	<b>3,542</b>
<b>CSHCN whose conditions cause financial problems for the family</b>	<b>18.5</b>	<b>3,062</b>
<b>CSHCN whose families spend 11 or more hours per week providing or coordinating health care</b>	<b>9.1</b>	<b>1,494</b>
<b>CSHCN whose conditions cause family members to cut back or stop working</b>	<b>18.1</b>	<b>2,988</b>

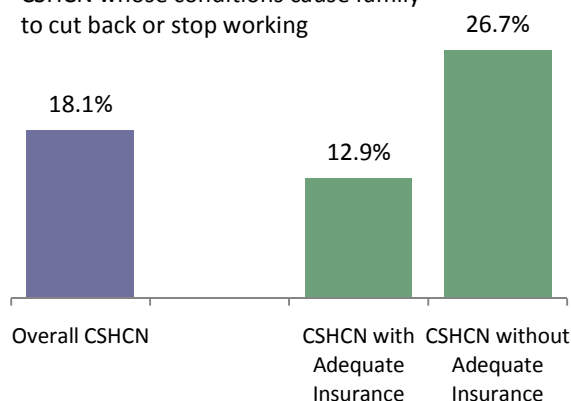
#### Impact on the Family:

CSHCN whose conditions cause financial problems for the family



#### Impact on the Family:

CSHCN whose conditions cause family to cut back or stop working



\* Child and Adolescent Health Measurement Initiative. 2005/06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. Retrieved 12/08/2010 from [www.cshcndata.org](http://www.cshcndata.org).

# Family Voices of NORTH DAKOTA

## *a Family-to-Family Health Information Center*

### Our Work:

Family Voices of North Dakota (FVND) has assisted families of CYSHCN since 1996, when Executive Director Donene Feist, a mother of a young child with hearing impairment, experienced the barriers in navigating health care systems. Since that time, FVND has grown to become an established resource for families and professionals and has received funding from Family Voices National, Children's Special Health Services, Centers for Medicare and Medicaid, and the Maternal and Child Health Bureau.

### Family Voices of North Dakota assists families:

- In navigating public and private systems, including health systems and insurance plans,
- In accessing services and resources for children and how to partner with providers and caregivers,
- By listening as they describe their encounters with systems and helping to guide them to possible solutions,
- By collaborating with families, health care providers, public and private agencies, and advocacy and/or support groups to promote family-centered care and medical homes for children with special health care needs,
- By providing 1:1 emotional and informational support through our ND Parent to Parent Program, and
- By promoting discussion and linkages among families, providers, managed care programs, and government to better serve the health care and related needs of children and families in North Dakota

The Family-to-Family Health Information Center is supported with funding from the Health Resources and Services Administration (HRSA)/Maternal and Child Health Bureau (MCHB)/Division of Services for Children with Special Health Needs (DSCSHN), through grant# 1 H84MC07992-01-00; ND Department of Health, CSHS; North Dakota State Council of Developmental Disabilities; NDIS, and NDDPI

### By The Numbers

From June, 2009 through May, 2010, Family Voices of North Dakota reported:

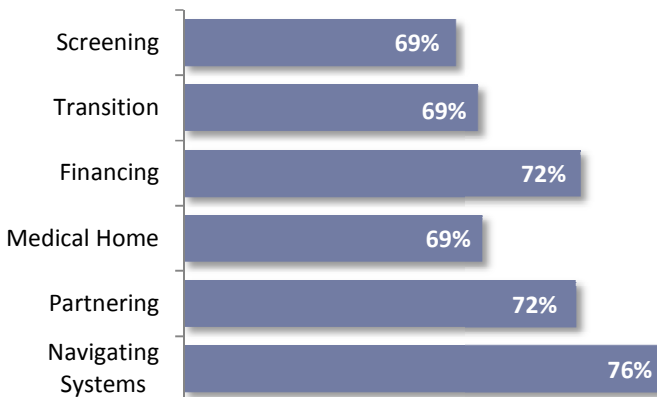
Families      Professionals

	Families	Professionals
<i>Requests for Assistance Received</i>	<b>2,772</b>	<b>1,390</b>
<i>People Reached through Trainings</i>	<b>1,128</b>	<b>1,036</b>
<i>People Reached through Newsletters</i>	<b>2,643</b>	<b>2,162</b>
<i>Materials Disseminated</i>	<b>32,871</b>	

### As a Result of Assistance /Training Provided by Family Voices of North Dakota F2F:

<i>% Families Reporting Better Able to Partner in Decision-Making</i>	<b>94%</b>
<i>% Families Reporting Better Able to Find and/or Learn about Community Services</i>	<b>93%</b>
<i>% Families Reporting More Confidence in Getting Health Care and Services Needed by Child</i>	<b>98%</b>

### Families Served by Outcome



*"Family Voices has supported my whole family by awareness, education, sibling support, medical information, resources, connections to other families and support, and just a voice to hear and listen. Every day I go to my computer to receive the information and support I need to better the lives of all of us in my family and the caregivers for Aaron. I found new friends because of Family Voices and I got more involved in my community."*